



Last Acts Partnership

Advocating Quality
End-Of-Life Care

REVITALIZING THE NATIONAL CENTER FOR HEALTH STATISTICS NATIONAL MORTALITY FOLLOWBACK SURVEY

Issue: End-of-life care is one of the most neglected public policy issues that faces us today; however, we lack the most basic details of how Americans spend their final months and days. A revitalized National Mortality Followback Survey (NMFS) would provide the information we must have if we are to improve care and plan intelligently for the health care needs of our aging population.

Unfortunately, inadequate funding of the overall vital statistics program at the National Center for Health Statistics (NCHS, in the Centers for Disease Control and Prevention) makes moving forward with a NMFS impossible. Currently, there is a shortfall in funding routine national mortality statistics, as well as other vital statistics programs.

Background: Over the past several years, the Institute of Medicine and Last Acts Partnership have studied issues surrounding care at the end of life. Recent reports by these organizations highlighted the limited data that currently exist; what we know about end-of-life care comes from a very small universe of studies and anecdotes. There is no systematically collected information on how well or badly people live the end of life across the country or across time. As the Nation's elderly population continues to grow—the number of seriously ill and dying people will increase, while the number of family caregivers decreases, placing additional demands on the health care system.

National Mortality Followback Surveys have been conducted six times by NCHS during the period 1961 through 1993, creating an invaluable source of data for policy makers and researchers. However, 10-year-old data cannot describe the experiences of people dying *today* or allow us to anticipate the needs for care in the future. Because NMFS uses interviews with the next of kin (or someone close to the decedent) for a sample of people who died in the previous year, the followback survey is the most cost effective and efficient way to gather information on end-of-life care and quality of life.

Need for a Revitalized NMFS:

?? The main uses for information on care at the end of life are for (1) **public accountability** (i.e., allowing policymakers, patients, families, and the public to hold organizations and individuals accountable for the quality of the care they provide to dying patients); (2) **internal quality improvement efforts** by clinicians and others directly responsible for end-of-life care to evaluate and improve what they are doing on a continuing basis and design training programs; and (3) **further research** on the effects of different clinical, organizational, and financing options for end-of-life care and on the effectiveness of alternative strategies for improving care and outcomes for patients and their families.

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- ?? Data from the survey would be in the public domain and freely available to researchers and policy makers within and outside the government.
- ?? The NMFS will create links with other relevant data sources, such as the Minimum Data Set (MDS, from the quarterly nursing home survey), Medicare data sets, and SEER data from the National Cancer Institute and other State tumor registry information. Linkage to other surveys will not only enhance the available information for research and monitoring, but also will provide a basis for assessing the validity of survey results by comparison with independent data sources.
- ?? The proposed NMFS will begin to address very specific issues of practical importance to the public and the government, such as:
 - o Rates of disability, long-term care,
 - o and chronic illness and their duration among survivors to various ages, or among decedents (for example, among decedents, the percent who ever used a nursing home, home care, were disabled, had diabetes, and the duration of each).
 - o Medicare utilization and cost for various medical conditions and types of persons (classified by ethnicity, race, gender, years of disability after age 65 years, etc.)
 - o Factors associated with the spend-down to Medicaid eligibility.
 - o Spending patterns for those dually eligible versus those eligible only for Medicare, by disease status, demographic characteristics, etc.
 - o Years of life and spending patterns before and after entering the Medicare hospice program.
 - o Classification of decedents, costs, treatment trajectories by category of condition, for example, sudden death, terminal illness (e.g., cancer), organ failure (e.g., congestive heart failure, chronic obstructive pulmonary disease), and frailty.
 - o Projections of chronic illness, disability, and long-term care for current and future cohorts, based on life-time experience of decedents.
 - o Consequences of changes in public policy such as the recent changes in financing home health care.

The proposal: The proposed revitalized NMFS would be carried out by NCHS and focus on the quality of life and quality of care during the final months of life. Unlike the previous NMFS, it would be *continuous* with core questions that would not change, so that changes could be measured over time. In addition, specific populations would be oversampled periodically to improve our understanding of patterns of care and quality across the population, e.g., differences in end-of-life care by race, ethnicity, urban versus rural residence, insurance status, and for different causes of death.

Proposed solution: Before a new NMFS can be planned and implemented, the national vital statistics program must be adequately funded to purchase a full year of vital statistics from the States. Within a fully funded NCHS, the annual cost of a continuous survey in constant dollars is about \$7.5 million as of the year 2004 in which the survey estimates were made. A six-year cycle would cost about \$39 million, taking into account inflation estimated at five percent per year. This figure includes linkages with Medicare claims data and possibly other databases.

For more information on this effort, please contact Judith Peres, Vice President, Policy and Advocacy, at 202.296.8071, x108 or jperes@lastactspartnership.org. Thank you.